PUBLIC HEALTH DATA STANDARDS CONSORTIUM
PHDSC
Promoting Standards Through Partnerships
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Testimony
before the Standards Subcommittee and Subcommittees on Population Health and Privacy, Confidentiality and Security, National Committee on Vital and Health Statistics (NCVHS)

Hearing on Public Health Data Standards
November 12, 2013

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the Public Health Data Standards Consortium

The Public Health Data Standards Consortium (PHDSC, the Consortium) is a national non-profit membership-based organization of federal, state, and local health agencies; professional associations; academia; public and private sector organizations; and individuals. Its goal is to empower the healthcare and public health communities with health information and health information technology (HIT) standards to improve individual and community health. The Consortium is committed to bringing a common voice from the public health community to the national efforts of standardization of health information for healthcare and population health.

With the support from the Centers for Disease Control and Prevention (CDC) and other agencies, PHDSC has been actively working on representing interests of federal, state and local public health agencies in developing and deploying HIT interoperability standards to support electronic data exchanges among Electronic Health Record Systems (EHR) systems, Laboratory Information Management Systems (LIMS) and public health information systems for public health services and surveillance activities.

PHDSC has been focusing on ***standardization*** of (a) communicable disease case reporting and laboratory reporting working together with the Council of State and Territorial Epidemiologists (CSTE) and the Association of Public Health Laboratories (APHL), (b) data exchanges for Early Hearing Detection and Intervention (EHDI) program, (c) administrative data reporting, and (d) occupational data for health reporting; ***representation*** of public health perspectives in the development of the Health Level Seven (HL7) EHR System Functional Model and Public Health Functional Profile; ***development and testing of interoperability standards*** for public health at the Integrating healthcare Enterprise (IHE); ***implementation of pilot projects*** on standards-based EHR-reporting to public health; ***coordination of HIT standards harmonization*** for public health through the Public Health Reporting Initiative (PHRI) of the Standards & Interoperability (S&I) Framework, Office of the National Coordinator for HIT (ONC); ***development of academic training*** on informatics and *HIT Standards and Systems Interoperability* for public health workforce in partnership with Johns Hopkins University; and ***development of web-based informational/educational resources*** including *PHDSC Web-based Resources Center on Public Health in HIT Standardization* and *HIT Standards Gateway* for the World Health Organization's eHealth Data Standardization and Interoperability Initiative.

We view standards as a key component of the infrastructure for public health services and surveillance activities across various levels of government. PHDSC has unique experience with assisting state and local agencies with deployment of standards-based HIT solutions that demonstrated effective use of EHR technology for public health data collection and bi-directional communication with providers. PHDSC methodology for assuring public health interests in the national and international HIT standardization activities developed through various projects supported by CDC and described in the *PHDSC Business Case*

on the Role of Public Health in HIT Standardization[1] is aimed to transition Public Health into the interoperable standards-based infrastructure that will help to maximize the performance and coordination of public health information systems and the effectiveness of available agency resources devoted to public health services and population health surveillance. Our answers to the Hearing's questions are based on a decade of hands-on experience with HIT standardization for Public Health.

- **Current state of public health related standards;**

Public Health, as well as the healthcare industry at large, are in a very early state of HIT standardization. Though HIT standards in Public Health have been under development for more than two decades, the development of interoperability standards, i.e., ensemble of various standards aimed to support business needs for collecting and sharing public health information, have started only in the last decade, specifically under the activities of the Health Information Technology Standards Panel (HITSP)[2] and the Integrating the Healthcare Enterprise (IHE).[3] As stated in the White Paper to the Senate entitled *Reboot: Re-Examining the Strategies Needed to Successfully Adopt Health IT*, "interoperability is the key to achieving efficiencies in care with health IT; however, interoperability has to date proven very difficult to establish."[4] According to the Public Health Reporting Reference Implementation Framework[5] developed by the Public Health Reporting Initiative of the ONC S&I Framework, only seven public health programs (communicable diseases [case reporting and laboratory reporting], early hearing detection and intervention [EHDI], cancer, immunization, healthcare associated infections [HAI], vital records and adverse event reporting) had started working on interoperability standards.[6] In the last year, the work on interoperability standards for administrative data and obesity data had started at IHE.

Those public health interoperability standards, however, are not yet mature. They have been tested and adopted by only a few public health vendors in their public health information systems products. The low adoption of interoperability standards results from

a) ***an unawareness*** about those standards as they are new to Public Health;
b) ***immaturity*** of these newly developed standards;
c) ***absence of funding and incentives for testing*** of interoperability standards by public health IT and EHR vendors;
d) ***absence of funding to transition*** from current non-standardized information systems to interoperable IT solutions;
e) ***absence of personnel*** capable to facilitate transition to standardized interoperable information systems in public health agencies at all levels of government

In the meantime, hundreds of millions of dollars are spent each year in Public Health to continue supporting non-standard IT solutions or supporting siloed program-specific IT implementations solving very similar problems that have already been solved in a multi-state, standards-based way.

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[1] Public Health Data Standards Consortium (PHDSC). Business Case on the Role of Public Health in HIT Standardization. 2009. URL: http://www.phdsc.org/standards/business_case.asp
[2] Health Information Technology Standards Panel (HITSP). URL: http://www.hitsp.org
[3] Integrating the Healthcare Enterprise (IHE). URL http://www.ihe.net
[4] Thune J, Alexander L, Roberts P, Burr R, Coburn T, Enzi M. Reboot: Re-Examining the Strategies Needed to Successfully Adopt Health IT. White Paper. US Senate. April 13, 2013.
[5] Integrating the Healthcare Enterprise (IHE). Quality research and Public Health Technical Framework. Resources. Profiles. URL: http://wiki.ihe.net/index.php?title=Profiles#IHE_Quality.2C_Research.2C_and_Public_Health_Profiles
[6] Public Health Reporting Initiative (PHRI). ONC Standards & Interoperability (S&I) Framework. PHRI Reference Implementation Framework. 2013. URL: http://wiki.siframework.org/Public+Health+Reporting+Initiative

- ***coordination of standards development activities***

PHDSC has been advocating for the need of coordination for standards development for public health since its inception. The methodology for such coordination has been described in 2009 in the *PHDSC Business Case on the Role of Public Health in HIT Standardization*.[7] To date, coordination of standards development activities has been done on a voluntary basis. To some extent on the advocacy level such coordination has been conducted by the Joint Public Health Informatics Task Force (JPHIT) helping to facilitate responses from public health professional organizations to the national regulations on standards; on the technical level such coordination has been conducted by PHDSC which collaborated with several public health associations on harmonization of their program-specific standards with the national standardization efforts. The Community-led Public Health Reporting Initiative of the ONC S&I Framework - a national forum aimed at harmonization and coordination of HIT standardization for Public Health - was originally supported by CDC. However, this support ceased in December 2012, and since then this critical HIT standardization in Public Health endeavor has been operating on a voluntary basis. However, today this is the only national initiative that is aimed at the coordination of HIT standardization in Public Health at ONC.

- ***representation and participation by public health in standards activities***

In 2009, for the development of the *Business Case* mentioned above, PHDSC conducted a survey on representation and participation of Public Health in standardization activities. The comparative analysis of data collected in 2013 with the 2009 baseline data showed that in the past five years, representation and participation of public health programs in various standards development organizations including Health Level Seven (HL7) and Accredited Standards Committee X12 and other remained on the same very low level as in 2009 resulting in few new standards developed for Public Health and underrepresentation of public health perspectives in the standards developed by these organizations.

Today, Centers for Disease Control and Prevention – the leading public health agency – does not have representation at the HIT Policy Committee and HIT Standards Committee. The level of public health participation in the S&I Framework Initiatives -- including PHRI Initiative, Structured Data Capture (SDC) Public Health Tiger Team and others during 2008-now has been lower than public health participation in the HITSP process during 2005-2009. The only positive dynamic during 2008-now could be seen with establishing a public health presence at the Integrating the Hhealthcare Enterprise (IHE) where with the small support from CDC several public health programs, e.g., EHDI, Vital Records, Cancer, Immunization, Occupational Health and a few others have been participating in the development of interoperability standards, IHE Connectathon's standards testing and Interoperability Showcases of the Health Information and Management Systems Society (HIMSS).

We call for more participation by public health programs, for which there should be incentives or more programmatic inventiveness to bring their programs to standardization efforts.

We believe that these incentives should be supplied by the Federal government because of the role the government should play in leading and facilitating the adoption of standards as outlined in the Federal Standardization Policies, Regulatory Framework and Federal Agencies' activities defined in the following documents:

1. National Technology Transfer and Advancement Act of 1995 (NTTAA) that calls to adopt voluntary consensus standards, wherever possible, in lieu of creating proprietary, non-

[7] Public Health Data Standards Consortium (PHDSC). Business Case on the Role of Public Health in HIT Standardization. 2009. URL: http://www.phdsc.org/standards/business_case.asp

consensus standards by federal agencies. URL: http://www.nist.gov/standardsgov/nttaa-act.cfm
2. Office of Management and Budget (OMB). Circular A-119, Federal Participation in the Development and Use of Voluntary Consensus Standards and in Conformity Assessment Activities. URL: http://www.nist.gov/standardsgov/omba119.cfm
3. Executive Office of the President. National Science and Technology Council. Federal Engagement in Standards Activities to Address National Priorities. Background and Proposed Policy Recommendations Subcommittee on Standards. Washington, DC. October 10, 2011. URL: http://www.nist.gov/standardsgov/upload/Federal_Engagement_in_Standards_Activities_October12_final.pdf
4. Principles for Federal Engagement in Standards Activities to Address National Priorities. Executive Office of the President, Office of Management and Budget, United States Trade Representative, Office of Science and Technology Policy. Memorandum for for Heads of Executive Departments and Agencies, 2012. URL: http://www.whitehouse.gov/sites/default/files/omb/memoranda/2012/m-12-08.pdf

We also believe that the incentives should be supplied by the Federal government because today the Federal government continues to fund the development and maintenance of various non-standardized public health information systems. This current funding stream should be align with the necessary transition of public health IT into the integrated, interoperable health IT infrastructure with the Public Health playing the role of equal and reliable partner of the electronic health information exchanges within the scope of its functions and authority.

In addition, we believe that the Federal government has to facilitate the growth of public-private partnership for Public Health to start a dialogue with the private sector in seeking and aligning incentives for public health standardization. Several vendors despite of a lack of funding have been transitioning into standards-based solutions. They see that "the primary barrier that exists is the perception that standards don't serve the unique needs of a particular PH jurisdiction. Though those states that adhere to standards and look more towards where their program-specific information systems are similar than they are different can take much better advantage of standards, get solutions more quickly implemented, and save millions of dollars in solving important problems."[8] We have to support those vendors as well as to promote and support the transition of other public health vendors into the standardized applications deployed in their products.

- ***where is public health strongest and where is it weakest***

Wherever public health programs come to the standardization process, they demonstrate high professionalism and commitment to serve the business needs of their programmatic public health communities. At the standardization tables at HL7, IHE, S&I PHRI and others we see strong efforts from the participating public health programs to collaborate with each other in the standard development process, harmonize program-specific standards, and learn about technologies that will enable electronic data reporting from EHR systems, and data sharing and re-use, implementing the "collect once use many times."

Here are a few specific examples of PHDSC projects that provided strong public health input into standardization process:

In the work for EHDI standards, we saw great collaboration between Federal CDC and State EHDI

[8] Todd Watkins, Scientific Technology Corporation (STC). Personal Communications, November 2013.

programs with the strong focus on serving the data needs of State EHDI programs and their stakeholders (families with children with special needs). EHDI program became the first public health program included in the Meaningful Use (MU) of HIT Stage 2 with standards for quality measure reporting.

In the work of using HL7 Clinical Document Architecture (CDA) standard recommended by the HIT Policy Committee as a future direction for standardization of public health reporting, [9] PHDSC in partnership with APHL, CSTE and IBM, successfully developed CDA-based public health case reports and laboratory reports for selected conditions. For the EHDI program, we developed CDA-based Newborn Hearing Screening Report and the Early Hearing Care Plan document. For the case reports, we used the opensource Model Driven Health Tool (MDHT)[10] to develop and publish the reports models in the MDHT document library – a repository that will allow vendors to get access to the standardized public health report models and jurisdiction-specific instances of condition-specific reports. We successfully piloted the transmission of CDA-based public health reports from clinical EHR systems to public health information systems in five jurisdictions [Delaware (*Tuberculosis*), New York State and San Diego County (*Pertussis*),[11] Oregon (*Newborn Hearing Screening Report*) and North Dakota (*Early Hearing Care Plan*).[12] These efforts were acknowledged by various media channels with the Forbes magazine stating that IBM, CDC and PHDSC are changing the way of public health reporting. (URL: http://www.forbes.com/sites/amywestervelt/2012/08/27/could-technology-help-stem-the-spread-of-whooping-cough/)

The development of the PHDSC Source of Payment Typology demonstrates what the public health community can bring to the standards table. The development of this value set along with the associated definitions for the payer categories highlights the ability of the public health community to identify data problems brought on by bad standards along with the ability to find and carry through with a positive solution. Currently, we are on track to get the Source of Payment Typology recognized as a value set mandated by the Health Information Portability and Accountability Act (HIPAA). That is one of the important public health contributions to harmonization of clinical and administrative data standards.

Our long standing product is the PHDSC Health Care Service: Data Reporting Guide. That again demonstrates the ability for the public health community to develop industry standards that speak to the needs of making good public health policy balanced against the burden such data collection has on the industry. The most recent development of the All Payer Claims Databases (APCD) to collect cost data from a large range of services is balanced against the industry burden to produce this data.

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[9] Health IT Standards Federal Advisory Committee. Recommendations from the Public Health Surveillance Summer Camp. September 28, 2011. URL: http://healthit.hhs.gov/portal/server.pt?open=512&objID=1817&parentname=CommunityPage&parentid=28&mode=2&in_hi_userid=11673&cached=true#09281

[10] Open Health Tools Model Driven Health Tools Project for CDA. URL: https://www.projects.openhealthtools.org/sf/projects/mdht/

[11] Public Health Data Standards Consortium (PHDSC). CDA for Public Health Pilot Project - Communicable Diseases. Project Report. 2012. URL: https://wiki.phdsc.org/images/2/22/PHDSC-CDA-for-PH-Pilot-Report-08-31-12FINAL.pdf.

[12] Public Health Data Standards Consortium (PHDSC). CDA for Public Health Pilot Project – Early hearing Detection and Intervention.. Project Report. 2012. URL: https://wiki.phdsc.org/index.php/EHDI-Pilot

The weakest areas for public health standardization are the following:

a) ***very low participation*** of public health programs from the Federal, State and Local agencies in the standards harmonization efforts, the development, testing and deployment of interoperability standards
b) ***absence of support for coordination and facilitation of public health standardization*** from the Federal, State and Local governments
c) ***absence of certification program*** for public health information systems
d) ***continued siloed approaches*** in HIT standardization for some programs

"Limited or non-participation by federal, state and local public health representatives in national HIT standardization ultimately means that public health needs for interoperable clinical and public health information systems are not served in the standards-based certified HIT products." [13]

- **What are the incentives and drivers for adopting and using public health data standards;**

The incentives and drivers for adopting and using HIT standards in public health are the same as the ones for the healthcare at large. Standards will facilitate the ***electronic sharing of data*** among health care providers and public health agencies to achieve the efficiencies of the agency operations, potential cost savings and quality improvements in delivering public health interventions, care coordination and public health response to the current and emerging public health threats. Standards will enable the robust and secure infrastructure capable to prevent any misuse of sensitive patient information. As hundreds of thousands of providers, from small family practitioners to very large hospital systems, all need to be using a network and IT infrastructure that allows for the sharing of information,[14] the public health agencies will be able to become an equal and reliable partner and user of such infrastructure.

Without standards, [15] the current non-standardized public health IT infrastructure:

- ***Threatens public health data gathering activities*** as fragmented public health information systems are unable to receive data electronically from clinical systems (EHR systems, LIMS, pharmacy systems, payer systems, etc.)
- ***Diminishes effectiveness of public health interventions*** as underreporting – caused by the inability to receive/exchange data electronically – reduces timeliness and effectiveness of public health services and responses, negatively affecting public safety
- ***Diminishes efficiency*** of public health operations due to continued redundancy of data gathering across programs and outdated information technology
- ***Reduces ability to communicate public health information back to clinicians*** electronically in real-time to inform clinical decisions, e.g., population health status and disease surveillance reports; information about public health resources; public health guidelines and recommendations; health educational materials; and other
- ***Jeopardizes adoption of modern interoperable HIT applications in public health***, as these applications lack functionality needed to address public health needs

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[13] Public Health Data Standards Consortium (PHDSC). Business Case on the Role of Public Health in HIT Standardization. 2009. URL: http://www.phdsc.org/standards/business_case.asp

[14] Thune J, Alexander L, Roberts P, Burr R, Coburn T, Enzi M. Reboot: Re-Examining the Strategies Needed to Successfully Adopt Health IT. White Paper. US Senate. April 13, 2013.

[15] Public Health Data Standards Consortium (PHDSC). Business Case on the Role of Public Health in HIT Standardization. 2009. URL: http://www.phdsc.org/standards/business_case.asp

- ***Jeopardizes achieving population-level healthcare goals*** as public health lacks the capacity to participate in electronic regional and nationwide health information exchanges with clinicians and cannot effectively provide population health information
- ***Minimizes the potential of state and local public health entities to receive funding from federal and other sources*** that will likely mandate use of interoperable HIT products
- ***Leaves the general population needlessly at-risk*** when lack of standardization means that public response to disaster, emerging threats (bio-terror, SARS, pandemic flu) is "invisibly handicapped."

The public health community understands the many ways that the current non-standardized framework severely reduces our collective ability to assess, understand and respond. While the public does not know what is "lost" or "missing," can we allow that fact to justify continued inaction.

- ***what are the barriers and challenges***

Similar to healthcare, the standards-based electronic data-sharing infrastructure for Public Health should be developed "to work with the hundreds of thousands of IT systems already in place. It must be flexible enough to accommodate future changes in technology. Additionally, it must be affordable and simple enough for the wide range of public health programs to implement." [16] We have identified seven barriers for adopting and using HIT standards in Public Health:

1. ***Lack of awareness about what standards to use and how to use them*** in the current fragmented public health information systems
2. ***Absence of coordination and facilitation*** of public health HIT standardization from the Federal government
3. ***Lack of federal, state and local agencies participation in the national HIT standardization activities*** to inform standard developers about public health needs
4. ***Limited ability to be involved in national efforts as federal, state and local agencies serve particular jurisdictions*** *or reflect* ***limited knowledge of needs in other jurisdictions, programs, and level***s of Public Health
5. ***Difficulty in identifying standardization entities (too many of them)*** that provide the greatest opportunity for addressing federal, state and local public health needs
6. ***Lack of technical knowledge and informatics skills*** to participate in the technical dialogue and to effectively translate public health needs into technical HIT standards
7. ***Lack of funding*** to support HIT standardization in Public Health and agencies' participation in HIT standardization.

These challenges, in turn, lead to

- ***Insufficient number of standards*** to serve public health needs
- ***Low level of maturity of existing standards***
- ***Low penetration (adoption) of standards-based products*** in public health information systems

[16] Thune J, Alexander L, Roberts P, Burr R, Coburn T, Enzi M. Reboot: Re-Examining the Strategies Needed to Successfully Adopt Health IT. White Paper. US Senate. April 13, 2013.

- **What is the state of information exchanges of public health data from EHR systems; what are the standards being used?**

Public Health is in the piloting stage of information exchanges with EHR systems. As it was described earlier, during 2012-2013, with the support from CDC, PHDSC conducted five pilot projects to deploy the HL7 CDA standard for EHR-based public health reporting of

- ***Communicable Diseases Case Report*** to the public health surveillance programs (*Tuberculosis* in Delaware; and *Pertussis* in New York State and San-Diego County)[17]
- ***Newborn Hearing Screening Report*** from birthing facility to the Oregon State EHDI program and
- ***Early Hearing Care Plan*** from the North Dakota EHDI program to pediatrician's EHR.[18]

These projects were also the first in the nation full scale pilot projects on the use of HL7 CDA standard for public health reporting. These were the first experience of receiving/exchanging standardized public health reports from/with EHR systems using CDA standard in participating jurisdictions. The HL7 CDA standard was named in the Meaningful Use of EHRs for data exchanges between clinical systems. In September 2011, the Health IT Standards Federal Advisory Committee recommended the use of the HL7 CDA standard as a future direction for electronic data exchanges between clinical and public health information systems for public health reporting.[19]

For the information content standards, in all five projects to populate public health reports from EHR data we used *HL7 Continuity Care Document (CCD)* standard for the content of the patient data and the *HL7 CDA standard* for the structured format of the public health report. Furthermore, for the communicable disease reporting pilot projects we used standardized case reports developed based on the *2009 HL7 Implementation Guide for CDA Release 2 on Public Health Case Reporting, Release.*[20] For the EHDI reporting pilot projects we used the *IHE Early Hearing Care Plan Content Profile* standard.[21]

For the information exchange standards, we used *IHE Retrieve Form for Data Capture Integration Profile* standard[22] in New York State and Oregon pilot projects. (This standard is currently used for the ONC S&I Framework Structured Data Capture (SDC) Initiative where the Public Health Tiger Team plans for the additional CDA pilot projects on communicable diseases, cancer and EHDI reporting.) We used *IHE Cross-enterprise Document Reliable Interchange (XDR) Integration Profile* standard[23] in the North Dakota pilot project.

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[17] Public Health Data Standards Consortium (PHDSC). CDA for Public Health Pilot Project: Communicable Disease Reporting. Project Report. 2012. URL: https://wiki.phdsc.org/images/2/22/PHDSC-CDA-for-PH-Pilot-Report-08-31-12FINAL.pdf. Accessed February 28, 2013.

[18] Public Health Data Standards Consortium (PHDSC). CDA for Public Health Pilot Project: Early Hearing Detection and Intervention (EHDI) Data Exchange. Project Report. 2013. URL: https://wiki.phdsc.org/index.php/EHDI-Pilot

[19] Health IT Standards Federal Advisory Committee. Recommendations from the Public Health Surveillance Summer Camp. September 28, 2011. URL: http://healthit.hhs.gov/portal/server.pt?open=512&objID=1817&parentname=CommunityPage&parentid=28&mode=2&in_hi_userid=11673&cached=true#09281

[20] Health Level Seven (HL7). Implementation Guide for CDA Release 2: Public Health Case Reporting, Release 1. US Realm. Informative Document. Published October 2009.

[21] Integrating the Healthcare Enterprise (IHE). Early Hearing Care Plan (EHCP) Content Profile. URL: http://wiki.ihe.net/index.php?title=Early_Hearing_Care_Plan

[22] Integrating the Healthcare Enterprise (IHE). Retrieve Form for Data Capture (RFD) Integration Profile. URL: http://wiki.ihe.net/index.php?title=Retrieve_Form_for_Data_Capture

[23] Integrating the Healthcare Enterprise (IHE). Cross-enterprise Document Reliable Interchange (XDR) Integration Profile. URL: http://wiki.ihe.net/index.php?title=Cross-enterprise_Document_Reliable_Interchange

- ***what are the drivers, and incentives***

Participants for the pilot projects were selected through the Call for Participation disseminated via communicable disease programs and State EHDI programs. In both programs we had about 30% response rate to the Call for Participation where about 15 % of the programs wanted to join as Participants and the rest as Observers. This demonstrated increased interest of public health programs to deploy EHR technology for public health reporting. Though small funding was available for the participants to implement the pilot projects, the main incentive was to obtain knowledge and hands-on experience with EHR-based reporting to public health. Based on our limited experience, we believe that the main incentive and driver for the use of EHR technology is the ability to exchange data between clinical and public health systems electronically thus enabling the delivery data for those who needs to know in real time.

- ***what are the challenges and issues***

From technical perspectives, we observed the following challenges:

- On the clinical side, the main challenge for implementing the pilot projects was the inability of EHR vendors to produce CDA documents to populate public health reports. We believe that this was due to the Meaningful Use priorities competing with the needs of Public Health. During the time of conducting EHDI CDA pilot projects, EHR vendors had been in the process of upgrading their systems to utilize standards including capabilities for the use of CDA standard. In some cases therefore, we had to work with test harnesses not real EHR systems. Despite this challenge, we did see the interest from EHR vendors to participate in CDA-based public health reporting pilot projects in the future after completing systems upgrades. For examples, several inquiries had been made to the S&I Public Health Reporting Initiative by other S&I Framework Initiatives that wanted to include public health reporting in their pilot projects.

- On the public health side, we did not see particular challenges with receiving CDA-based public health reports. Moreover, we saw that the current State public health IT infrastructure is capable of processing CDA documents received through the State public health gateways using Orion Rhapsody technology and to channel the reports to the program-specific public health surveillance systems.

The ***main challenge*** for both clinical participants (senders) and public health participants (receivers) of EHR-based reporting (reverse order between senders and receivers in the North Dakota project), with the small exception of vendors participating in IHE Connectation and HIMSS Interoperability Showcases, was the ***overwhelming and alarming lack of awareness about standards***, in general, and CDA-specific standards (both content and information exchange standards), in particular. The majority of time on the projects was spent on educational and informational efforts to bring participants (program staff and technical IT staff) into the standards world.

- **What are implementation challenges from the public health agency perspective; what are the needs (technical, resources, education, etc) to advance adoption and use of standards by public health agencies**

Based on the experience with conducting the pilot projects as well as an over-the-decade experience with participation in the HIT standardization efforts, we see the following implementation challenges and needs for standards adoption from the public health agency perspectives:

Standards

- ***Lack of standards and, especially, interoperability standards*** to support public health practices and research
- ***Low level of maturity*** of existing standards

Standards-based Products

- ***Absence of public health information systems certification program*** to assure that standards-based IT products are used in Public Health
- ***Lack of incentives*** for both EHR and public health IT vendors to transition to costly standards-based IT solutions for public health reporting and data sharing

Personnel/Workforce

- ***Lack of IT personnel*** with overall awareness and required technical knowledge about HIT standards
- ***Lack of program personnel*** with overall awareness and needed business and technical knowledge on HIT standards to communicate program (user) needs into the standard development process
- ***Almost absolute absence of personnel designated to represent the agency's interests/perspectives*** in the national HIT standardization initiatives, at the Federal, State and Local levels.

Infrastructure

- ***Absence of the national infrastructure needed to support HIT standardization in Public Health*** including:
  - ***no process for identifying and prioritizing the need for HIT standards*** for Public Health - all current activities are ad hoc, they depend today on the interest, leadership, and vision of certain individuals within the federal government rather than on the alignment with the Healthy People 20X20 goals or Learning Health System goals
  - ***no infrastructure for coordination*** of standards development, maintenance and cross-harmonization of standards developed for specific public health programs and levels of government
  - ***no infrastructure for continuing maintenance*** of already developed standards
  - ***no infrastructure for coordination of standards deployment*** such as
    - no public health information systems certification program(s)
    - no entity (laboratory, deployment workshop, etc.) for sharing experience and lessons learned with the deployment of standard-based solutions

Funding

- ***Absence of funding to support HIT standardization in Public Health*** that results in the following challenges related to the workforce and HIT standardization infrastructure:

  Public Health Workforce on HIT Standards

  - ***no HIT standards personnel positions*** in agencies to lead and coordinate standardization

efforts within the agency and with health information exchange partners
- ***no support for participation of the agencies' lead/liaisons/representatives*** in the HIT standardization entities
- ***no support for the primary and continuing education on HIT standards***[24] for both program staff and IT staff, especially with the closure of the ONC funded University-based Training Grants

Public Health Infrastructure on HIT Standards
- ***no support of the establishment of the national infrastructure on HIT standardization*** for Public Health including the development and maintenance of (a) the repository of regulatory documents on public health standardization and (b) Public Health Reporting and Data Exchange Knowledgebase of public health reporting guidelines, reporting triggers, common public health data models integral with the clinical data, repository of interoperability standards, tools for testing, certification and deployment of standardized IT products
- ***no support for the coordination of the standardization efforts between public health agencies at all levels of government***
- ***no support for the coordination of the standardization efforts between public health agencies and its partners/stakeholders in health information exchanges*** such clinical and non-clinical entities who submit data to public health and use public health data in their services

- **How is privacy and security covered in public health data standards? Are there privacy and security elements embedded in the standards? Is privacy and security under a different workflow process?**

We believe that privacy and security are an essential requirement for the electronic data reporting and data sharing for Public Health. Privacy and security are not under a different workflow process but are an embedded step(s) in the flow of events of every use case for which standards are developed. In the IHE public health content profiles, consent standards and other privacy and security standards[25] are embedded in the standards.

- **What security standards should apply to what types of data possessed by public health?**

In 2012, PHDSC in partnership with APHL and the support from CDC published the White Paper entitled *Assure HIT Standards for Public Health.*[26] Part 1 of the White Paper entitled *HIT Standards in Public Health Laboratory Domain*[27]contains Appendix 2 with the list of security standards for public

[24] Orlova AO. Health Information Technology Standards and Systems Interoperability Course. Johns Hopkins University. Open Courseware. URL: http://ocw.jhsph.edu/index.cfm/go/viewCourse/course/InfStandards/coursePage/index/
[25] Public Health Data Standards Consortium (PHDSC). Assure Health IT Standards for Public Health. White Paper Part 1: Health IT Standards for Public Health Laboratory Domain. 2012. URL: http://www.phdsc.org/standards/pdfs/PHDSC-APHL_PHL_Standards_White-Paper_Part-1FINAL_v1.pdf
[26] Public Health Data Standards Consortium (PHDSC). Standards for Public Health Laboratory Data Exchange. URL: http://phdsc.org/standards/phlab-data-exchange.asp
[27] Public Health Data Standards Consortium (PHDSC). Assure Health IT Standards for Public Health. White Paper Part 1: Health IT Standards for Public Health Laboratory Domain. 2012. URL: http://www.phdsc.org/standards/pdfs/PHDSC-APHL_PHL_Standards_White-Paper_Part-1FINAL_v1.pdf

health laboratory domain. We believe that these security standards are also applicable to other public health programs/domains.

- **What interoperability standards are needed for transfer of data from electronic health records to public health?**

With the HITSP efforts during 2005-2008, we learned about the interoperability standards. To support the charge of the Biosurveillance Use Case from the American Health Information Community (AHIC) to "*transmit essential data* <about 40 data elements> *from electronically enabled healthcare to authorized public health agency in real time*," the HITSP Biosurveillance Interoperability Specification (IS) 02[28] specified 107 standards that should work together to support interoperability (Table 1)."

Table 2. Biosurveillance Use Case: Number of Standards by Category

Standards Categories	Number of Standards
Data Standards	28
Information Content Standards	17
Information Exchange Standards	46
Identifiers Standards	11
Privacy and Security Standards	5
Functional Standards	0
Total	107

Naming one individual standard, e.g., HL7 2.5.1 for laboratory reporting, immunization and syndromic surveillance in MU Stage 1 regulation, could not enable interoperability when other standards (Table 1) were not specified.

IHE has continued working on developing interoperability standards including interoperability standards for public health in several public health domains/programs including early hearing detection and intervention (EHDI), cancer, immunization, vital records, occupational health and obesity (healthy weight).

As it was stated above, interoperability standards, i.e., ensemble of individual standards (Table 1) or "grouping" of individual standards in IHE terms, should become the priority for public health standardization.

PHDSC has been working with the ONC S&I Public Health Reporting Initiative to develop an educational series to inform/educate public health community about individual standards and interoperability standards to support standards-based electronic communication between Public Health and its stakeholders.

[28] Information Technology Standards Panel (HITSP). Biosurveillance Interoperability Specification (IS-02). URL:http://www.hitsp.org/InteroperabilitySet_Details.aspx?MasterIS=true&InteroperabilityId=49&PrefixAlpha=1&APrefix=IS&PrefixNumeric=02